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ABSTRACT

This collection of annotated bibliographies focuses on a broad spectrum of legal issues, and is drawn from a national database of current programs and literature regarding adolescents with chronic illnesses and other disabilities. Bibliographic materials listed include documents and articles concerning the following: consent and confidentiality issues (9 references); reproductive rights and adolescent sexuality (11); civil rights and public policy (7); vocational issues and habilitation rights (7); general legal issues and concerns for health care professionals (12); guardianship, estate planning and special tax considerations (6); legal and ethical issues of dying (6); and the criminal justice system and adolescents with disabilities (13). Other periodicals and resource listed (14) include summaries of legislation, listings of legal aid programs, tax brochures and parent guides. Four advocacy agencies are also described with contact information. (PB)

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National
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Youth with Disabilities

Welcome to this issue of *CYDLINE* Reviews, a publication of the National Center for Youth with Disabilities (NCYD). This issue focuses on a variety of legal issues that face adolescents and young adults with chronic and disabling conditions, their parents, advocates and the professionals who work with them. Our society has, for better or worse, become more and more enmeshed with the "legal system," using that term in its broadest context. During the past twenty years, the rights of people with disabilities expanded greatly; accompanying legal liabilities have been created where none previously existed. New and more complex legislation emerges every year from Congress and state legislatures. Adolescence, that legal gray area between childhood and adult status, adds another level of complexity. The goal of this publication is not to make the reader a legal expert but rather to raise awareness of the many legal implications involved in living in our complex world for adolescents and young adults with disabling conditions, their families and the professionals who serve them. Accordingly, the publication presents an overview of some of they key legal issues, ranging from consent and confidentiality to the criminal justice system.

For those new to these reviews, this collection of annotated bibliographies is drawn from NCYD's National Resource Library. The National Resource Library is a computerized, comprehensive database containing information about youth with chronic illnesses and disabilities, and it includes up-to-date expertise, programs, and literature of all relevant disciplines. Issues of *CYDLINE* Reviews that may be ordered are:

- ***Transition from Pediatric to Adult Health Care for Youth with Disabilities and Chronic Illnesses***
- ***Adolescents with Chronic Illnesses—Issues for School Personnel***
- ***Promoting Decision-Making Skills by Youth with Disabilities—Health, Education, and Vocational Choices***
- ***An Introduction to Youth with Disabilities (In English or Spanish)***
- ***Substance Use by Youth with Disabilities and Chronic Illnesses***
- ***An Introductory Guide for Youth and Parents (In English or Spanish)***
- ***Issues in Sexuality for Adolescents with Chronic Illnesses and Disabilities***
- ***Vulnerability and Resiliency: Focus on Children, Youth, and Families***
- ***Youth with Disabilities and Chronic Illnesses: International Issues***
- ***Race and Ethnicity: Issues for Adolescents with Chronic Illnesses and Disabilities***
- ***Recreation and Leisure: Issues for Adolescents with Chronic Illnesses and Disabilities***
- ***Sports and Athletics: Issues for Adolescents with Chronic Illnesses and Disabilities***
- ***Issues in Nutrition for Adolescents with Chronic Illnesses and Disabilities***
- ***Developing Social Skills: Issues for Adolescents with Chronic Illnesses and Disabilities***
- ***Legal Issues for Adolescents with Chronic Illnesses and Disabilities and Their Families***
- ***Self-Esteem: Issues for Adolescents with Chronic Illnesses and Disabilities***

Nearly 200 journals are regularly reviewed as are relevant books and non-published materials. New entries are added to the library on a regular basis. Topics in the Bibliographic File include chronic illness or disabling conditions; psychosocial issues; social issues; developmental processes; family; sexuality; education; employment and vocational rehabilitation; community and independent living; service approaches; professional issues; and policy, planning, and legal rights issues.

In addition to the Bibliographic File, the National Resource Library also includes a Program File with information about model programs throughout the country; an Educational Materials File with information on resources for professional development and programming usage; and a Technical Assistance File containing names and background information on consultants with expertise valuable to those involved with youth with disabilities.

You may request customized searches of the NCYD Resource Library on topics of your choice simply by calling an NCYD Information Specialist. The requested information will be sent to you in a format similar to this bibliography. In this way, you can easily receive current information on youth with disabilities which is specific to your particular needs and interests. NCYD has other publications available: *Connections* (a newsletter published three times a year); and *F.Y.I. Bulletin* (Fact Sheets presenting statistical and demographic data illustrated with tables, charts, and graphs). If you wish to receive a Publications List or would like information about the Resource Library, our Center can be reached (toll-free in the United States) at **1-800-333-6293, 612-626-2825**, or **TDD 612-624-3939.**

Thank you for your interest in NCYD. We hope you will take the time to read through this issue of NCYD's *CYDLINE* Reviews and share the contents with others.

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BIBLIOGRAPHIC MATERIALS

LEGAL ISSUES RELATED TO THE PROVISION OF MEDICAL AND PSYCHOSOCIAL SERVICES

Consent And Confidentiality Issues

AUTHOR Bicknell DJ.
TITLE **Consent for children and adolescents who have an intellectual handicap.**
SOURCE *Archives of Disease in Childhood* 1989 Nov; 64(11):1529-32.

ABSTRACT The author considers the laws surrounding consent for children and adolescents with intellectual disabilities, focusing especially on those over the age of 16 who cannot give consent. To ensure the best possible decisions, he suggests involving not only the patient, parent, and medical practitioner but also an ethics committee, lawyer and human rights activist. Previous laws and court decisions should also be considered.

AUTHOR Cohen DG.
TITLE **Treatment refusal in adolescents.**
SOURCE *Seminars in Oncology Nursing* 1986 May;2(2):112-6.

ABSTRACT This article discusses non-compliance on a continuum from complete refusal of treatment to unwillingness to cooperate with a specific aspect. This issue is particularly important when teens reach the age of consent. Two case studies are used to illustrate the factors associated with non-compliance: intrapsychic issues, peer relationships, family issues, and religion. The clinical implications of treatment refusal and possible interventions are described.

AUTHOR English A.
TITLE **Treating adolescents. Legal and ethical considerations.**
SOURCE *Medical Clinics of North America* 1990 Sep; 74(5):1097-1112.

ABSTRACT The author notes that adolescents who are legally minors are granted greater autonomy in health care than in many other areas. The developmental status of adolescents raises legal and ethical issues, particularly for health care professionals working with special populations such as adolescents with mental retardation. Topics addressed include: consent required for treating adolescents; confidentiality and disclosure; and sources of payment for care.

AUTHOR Erickson S; Hopkins MA.
TITLE **Gray areas: Informed consent in pediatric and comatose adult patients.**
SOURCE *Heart and Lung* 1987 May; 16(3):323-5.

ABSTRACT The authors discuss the principle of informed consent in pediatric and comatose adult patients. The child not being of "adult years" or the comatose adult not being of "sound mind" does not mandate a conclusion of total incompetence. Both patients should be included in the decision making to the fullest extent possible (using living wills or proxies in the case of the comatose adult). To ensure informed consent, pertinent information must be fully disclosed in a manner that the patient or proxy can understand.

AUTHOR Holder AR.
TITLE **Minors' rights to consent to medical care.**
SOURCE *JAMA (Journal of the American Medical Association)* 1987 Jun; 257(24): 3400-2.

ABSTRACT The author, a lawyer, provides an overview of the issues surrounding a minor's right to consent to--and refuse--medical care. Included in the analysis are categories of minors, statutory provisions as to minors' consent and the controversial area of reproductive health care, especially contraception and abortion.

AUTHOR Lesko LM; Dermatis H; Penman D; et al.
TITLE **Patients', parents', and oncologists' perceptions of informed consent for bone marrow transplantation.**
SOURCE *Medical and Pediatric Oncology* 1989; 17(3):181-7.

ABSTRACT The researchers found that informed consent promoted a healthier relationship between the patient and physician. The study also showed that full disclosure of information regarding medication treatment created neither a lack of faith in the treatment nor a feeling of being overwhelmed by medical jargon, but rather fostered a more positive and autonomous decision-making process. The researchers also offer suggestions to facilitate the informed consent process.

AUTHOR Morrissey JM; Hofmann AD; Thrope JC.
BOOK ***Consent and confidentiality in the health care of children and adolescents: A legal guide.***
SOURCE Free Press: New York, 1986:273.

ABSTRACT This book presents a historical overview of parent/child relationships, law, informed consent and rights to privacy. It describes principles of consent laws and cites examples. Considerations in the management of minors' health records are analyzed, and strategies to prevent conflicts and avoid adverse legal complications are offered. A state-by-state guide to information about minors' consent is included.

AUTHOR Plotkin R.
TITLE **When rights collide: Parents, children, and consent to treatment.**
SOURCE *Journal of Pediatric Psychology* 1981 Jun; 6(2):121-30.

ABSTRACT Historically, parents have had virtually the absolute right to consent to health care services for their children. Where the interests of the parents and their children differ, this common law rule has had less than ideal consequences and has often left health care professionals in a legal dilemma. This article reviews the legal literature in this area and identifies four major areas where the law permits treatment without parental consent. The author concludes that in most cases all parties—adolescents, parents and health care professionals—would be better served by lowering the statutory age of consent for medical and mental health services.

AUTHOR Sigman GS; Kraut J; La Puma J.
TITLE **Disclosure of a diagnosis to children and adolescents when parents object. A clinic ethics analysis.**
SOURCE *American Journal of Diseases of Children* 1993 Jul; 147(7):764-8.

ABSTRACT The authors present a case study to illustrate the ethical dilemma physicians encounter when parents of children and adolescents request that diagnosis or prognosis not be disclosed. Clinical factors regarding truthful disclosure are discussed and applied to the case of a young woman with cystic fibrosis. The authors suggest that disclosure is context-specific and depends upon consideration of changing physicians, disease specifics, patient and family factors.

Reproductive Rights and Adolescent Sexuality

AUTHOR Brahams D.
TITLE **Legal power to sterilise incompetent women.**
SOURCE *Lancet* 1989 Apr 15; 1(8642):854-5.

ABSTRACT Several British and Australian cases are cited concerning sterilization of women with mental disabilities. The view held by the author parallels the "in re D" (1976) case ruling that the court is to intervene and protect the female from sterilization even if the parent has good intentions. The patient's best interest and welfare must be secured.

AUTHOR Carter PI; St. Lawrence JS.
TITLE **Adolescents' competency to make informed birth control and pregnancy decisions: An interface for psychology and the law.**
SOURCE *Behavioral Sciences & the Law* 1985 Summer; 3(3):309-19.

ABSTRACT The authors submit that the social and legal view of adolescents' competency to reach reproductive health decisions is ambiguous at the present time, although increased adolescent sexual activity is a reality. Although the courts have given adolescents certain limited rights in birth control and pregnancy termination decisions, these legal decisions have been based on constitutional law rather than empirical evidence. When the basic issues of birth control and pregnancy termination are extracted from the emotion that surrounds them, the questions in need of answers are, the authors argue, amenable to empirical study. Unfortunately, few if any studies have been undertaken.

AUTHOR Elkins TE; McNeeley SG; Punch M; et al.
TITLE **Reproductive health concerns in Down syndrome: A report of eight cases.**
SOURCE *Journal of Reproductive Medicine* 1990 Jul; 35(7):745-50.

ABSTRACT The authors present eight case reports representing a variety of sexual, social, gynecologic, and reproductive health concerns of adolescents and adults with Down syndrome. Issues raised include: menstrual hygiene, premenstrual syndrome, contraception/sterilization, social skill development, sexual decision making, companionship, and marriage. Implications for health care professionals are included.

AUTHOR Gillon R.
TITLE **On sterilising severely mentally handicapped people.**
SOURCE *Journal of Medical Ethics* 1987 Jun; 13(2):59-61,

ABSTRACT Gillon argues for the case of sterilizing people with severe mental disabilities. He submits this would allow for sexual and social development without complications of pregnancy, and would not in any way be similar to sterilizations performed under Hitler's Third Reich. Regarding the rights of the severely disabled, he argues that sterilization could very well be in their best interest.

AUTHOR Haavik SF; Menninger KA.
BOOK ***Sexuality, law and the developmentally disabled person: Legal and clinical aspects of marriage, parenthood, and sterilization.***
SOURCE Paul H. Brookes: Baltimore, 1981:191.

ABSTRACT This book presents research data, legal analysis, and programmatic recommendations concerning sexuality, marriage and reproduction for persons with developmental disabilities.

AUTHOR Johnson B.
TITLE **Family planning for mentally handicapped girls.**
SOURCE *British Journal of Hospital Medicine* 1987 Nov; 38(5):481.

ABSTRACT The author presents a case scenario in which the parents of a 16-year-old girl with mental retardation were concerned about the girl's risk of pregnancy. The girl was about to enter a group living situation which would greatly increase opportunities for sexual activity. Legal constraints against sterilization and other invasive procedures (e.g., the IUD) are discussed as are practical constraints against oral contraceptives. The author asserts that current legal guidelines in Great Britain are overly restrictive in their attempt to protect the patient's civil rights.

AUTHOR Margolin KN.
TITLE **Risks of a privacy policy by residential institutions for handicapped adolescents.**
SOURCE *Journal of Rehabilitation* 1988 Apr; 54(2):50-54.

ABSTRACT Two hundred professionals met to discuss sexual exploration and expression by youth with disabilities living in residential facilities. This article considers the legal implications for institutions deciding to provide privacy for older youth with disabilities and provides practical suggestions as to how such a policy best can be implemented.

AUTHOR Passer A; Rauh J; Chamberlain A; et al.
TITLE **Issues in fertility control for mentally retarded female adolescents: II. Parental attitudes toward sterilization.**
SOURCE *Pediatrics* 1984 Apr; 73(4):451-4.

ABSTRACT This study found that 46% of the parents interviewed had considered sterilization for their adolescent daughters with mental retardation (MR); 26% were still seeking such surgery. Severity of mental retardation correlated with interest in sterilization; interest in sterilization also correlated with difficulty in teaching menstrual hygiene. Although parents of adolescents with mild MR most often sought tubal ligation, parents of youth with severe MR sought hysterectomy due to their concerns over menstrual management. Eighty-five percent of the parents favored laws enabling conditional, limited sterilization.

AUTHOR Petersen K.
TITLE **The family v. the family court: Sterilisation issues.**
SOURCE *Australian Journal of Public Health* 1992 Jun; 16(2):196-201.

ABSTRACT The author raises the issue of whether sterilization of minors with severe disabilities is "therapeutic." Various Australian court cases are mentioned and discussed briefly. A need to establish procedures and guidelines is noted, and an alternative plan is given. The plan includes the court's appointment of a trained mediator to assist the parties in resolving conflicting positions and a separate representative to present evidence to the court on all matters relevant to the minor's welfare.

AUTHOR Rauh JL; Dine MS; Biro FM; et al.
TITLE **Sterilization for the mentally retarded adolescent: Balancing the equities. The Cincinnati experience.**
SOURCE *Journal of Adolescent Health Care* 1989 Nov; 10(6):467-72.

ABSTRACT The authors discuss sterilization for the adolescent with severe disabilities. Included are a few individual cases as well as a review of state statutes and court laws. In presenting their view, the authors advocate a voluntary sterilization act, which (after extensive review by ethics, medical, social and legal committees) would allow sterilization for those unable to give consent.

AUTHOR Shore DA; Gochros HL.
BOOK ***Sexual problems of adolescents in institutions.***
SOURCE Charles C. Thomas: Springfield, IL, 1981:239.

ABSTRACT The book explores issues from historical, social, management, and clinical perspectives. A section on special populations includes chapters on youth with emotional disturbance, mental retardation, chronic illness, and physical disability. Topics include: ethics, civil rights, legal and administrative concerns, staff training, sex education, sexual contact between staff and youth, changing dysfunctional behavior, homosexuality, and human sexuality groups.

Civil Rights And Public Policy

AUTHOR Connelly JJ.
TITLE **The segregation of an adolescent in foster care who is HIV seropositive and developmentally disabled.**
SOURCE *Mental Retardation* 1989 Aug; 27(4):241-3.

ABSTRACT This article presents the case of an adolescent male who has mental retardation and a positive blood test for HIV infection. A long and complicated legal battle highlights the issues of adolescents' civil rights, segregating persons infected with the AIDS virus, violations of confidentiality, invasion of privacy, and discrimination. Recommendations are made for developing policies for foster care placement of individuals who are HIV positive and have developmental disabilities.

AUTHOR Crocker AC; Cohen HJ; Kastner TA.
TITLE ***HIV infection and developmental disabilities.***
SOURCE Paul H. Brookes: Baltimore 1991:336.

ABSTRACT Researchers and service providers discuss the topic of HIV infection. Three areas are considered: child and family; youth and adults; and policy guidelines. Vital medical, social, legal, and educational issues are raised with particular attention given to youth with disabilities.

AUTHOR Gerry MH.
TITLE **Section 504 of the Rehabilitation Act, HIV and AIDS: Legal implications.**
SOURCE *Issues in Law and Medicine* 1988 Fall; 4(2):175-90.

ABSTRACT This article features an in-depth discussion and analysis of Section 504 of the 1973 Rehabilitation Act. Specifically, the author discusses the law as it relates to protecting the rights of people who test positive for the HIV virus or have related illnesses and their rights to obtain services from health care providers who receive federal funds. Also included are explanations of the requirements of Section 504, definitions of key terms ("handicap;" impairment"), services governed by the law and the types of discrimination prohibited by Section 504.

AUTHOR Jaffe LR; Wortman RN.
TITLE **The fear of AIDS; Guidelines to the counseling and HTLV-III antibody screening of adolescents.**
SOURCE *Journal of Adolescent Health Care* 1988 Jan; 9(1):84-6.

ABSTRACT The authors offer guidelines in adolescent counseling and HTLV-III Antibody screening for those at risk for AIDS. They suggest that physicians discuss prevention of future infection and the use of safer sex practices with their patients and advise them to communicate their sexual history to their partner(s).

AUTHOR Smith PS; Goldman DS.
TITLE **Care of the young hemophiliac. New socioeconomic demands and the changing patient-physician relationship.**
SOURCE *American Journal of Pediatric Hematology/Oncology* 1985 Summer; 7(2):165-74.

ABSTRACT Discussion of legal and ethical issues including access to care, allocation of resources, avoidance of harm, informed consent, confidentiality and paternalism. Six case examples are used..

EDITOR Turnbull HR; Ellis JW; Brooks PO; et al.
BOOK **The least restrictive alternative: Principles and practices.**
SOURCE *American Association of Mental Deficiency*: Washington, DC, 1981:76.

ABSTRACT Presentation of concepts of least restrictive alternatives (LRA) as a principle of law, e.g., "due process," minimum intrusion, as applied to mentally retarded citizens and the right to consent to or refuse treatment. LRA is an appropriate tool to reduce unnecessary governmental restrictions in the lives of individuals.

AUTHOR U.S. Congress, Office of Technology Assessment.
TITLE **Adolescent Health-Volume I: Summary and policy options.**
SOURCE U.S. Government Printing Office: Washington, DC, 1991, Apr:202.

ABSTRACT This report from the Office of Technology Assessment (OTA) reviews the physical, emotional, and behavioral health status of contemporary American adolescents. This is one of three volumes. Volume I summarizes the findings of OTA's report and presents policy options; it also summarizes findings and policy options from Volumes II and III. Volume II addresses prevention and treatment services; Volume III addresses delivery of health and related services. Available from the Superintendent of Documents, Government Printing Office (052-003-01234-1). Purchase: $9.50.

Vocational Issues and Habilitation Rights

AUTHOR Bannerman DJ; Sheldon JB; Sherman JA; et al.
TITLE **Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap.**
SOURCE *Journal of Applied Behavior Analysis* 1990 Spring; 23(1):79-89.

ABSTRACT This article discusses the relationship between the right to habilitation and the right to personal liberties for clients with developmental disabilities. Service providers may easily deny personal liberties to a client, usually in an attempt to meet standards, be cost effective or satisfy individuals other than clients. Arguments opposing and in favor of the right to choice are presented. The authors believe that choice and habilitation need not necessarily be in conflict. Clients should be taught how to make choices, and choice should be an integral part of habilitation training procedures.

AUTHOR Colman W.
TITLE **The evolution of occupational therapy in the public schools: The laws mandating practice.**
SOURCE *American Journal of Occupational Therapy* 1988 Nov; 42(11):701-5.

ABSTRACT A review of the evolution of occupational therapy in the public schools as mandated by law. The role of occupational therapy is further defined as an integration of medicine, rehabilitation, and education. The author also notes the government's responsibility in the education of children and youth with disabilities.

AUTHOR Daniels M.
TITLE ***Employment law guide to the Americans with Disabilities Act.***
SOURCE Prentice Hall Law and Business: Englewood Cliffs, NJ, 1992:258.

ABSTRACT A comprehensive analysis of the Americans with Disabilities Act (ADA). This text analyzes and discusses key issues, employment provisions, regulations, interpretation, enforcement, merits of different solutions, and legislative history. Also included is an explanation of how the Equal Employment Opportunity Commission (EEOC) intends to interpret and enforce the employment provisions of the ADA. Periodic supplementation will update this publication.

AUTHOR Kalscheur JA.
TITLE **Benefits of the Americans with Disabilities Act of 1990 for children and adolescents with disabilities.**
SOURCE *The American Journal of Occupational Therapy* 1992 May; 46(5):419-26.

ABSTRACT The Americans with Disabilities Act (ADA) mandates changes in the physical and social environments to allow persons with disabilities to participate in life's activities without discrimination. The ADA is discussed in relation to occupational therapy practice. An environment-centered model is presented in place of the existing deficit-reduction model. This model emphasizes consultation and education to businesses and individuals for the purpose of altering environments to accommodate children and adolescents with disabilities.

AUTHOR Matthews DJ; Meier RH; Bartholome W.
TITLE **Ethical issues encountered in pediatric rehabilitation.**
SOURCE *Pediatrician* 1990; 17(2):108-14.

ABSTRACT A discussion of the biomedical ethics involved in maximizing the outcome in pediatric rehabilitation. Ethical issues include: autonomy, education, normalization, non-malificence, beneficence, treatment selection, quality of life, allocation of services, justice, treatment options, and financial considerations.

AUTHOR Walsh MA.
TITLE **Ch. 688 -- Transitioning from special education into human services.**
SOURCE Paper presented at the National Conference on Secondary, Transitional and Postsecondary Education for Exceptional Youth (Boston, MA, March 7-9, 1985). 7p.

ABSTRACT Under Massachusetts statutes, chapter 688, also known as the "turning 22 law," older adolescents and young adults with special needs beyond their 22nd birthday are provided with a two-year transitional process to plan for habilitative services. Eligibility criteria necessary in order to receive these transition benefits include: need for continuing services and an inability to work 20 or more hours per week. An interview/evaluation is also necessary in some cases. This innovative law is the first of its kind in the nation. Available through Educational Resources Information Center (ERIC) Doc. No. ED259544.

AUTHOR Wehman P.
BOOK ***Life beyond the classroom: Transition strategies for young people with disabilities.***
SOURCE Paul H. Brookes: Baltimore, 1992:464.3

ABSTRACT A comprehensive overview of issues surrounding transition from school to employment for young people with disabilities. Educational, legal, and social issues are discussed. The book covers service delivery systems, public schools, and vocational training. Federal regulations are discussed throughout as they pertain to development of programs. Each chapter features sample forms, tables, charts, and case studies.

General Legal Issues and Concerns for Health Care Professionals

AUTHOR Foley MK.
TITLE **Children with cancer: Ethical dilemmas.**
SOURCE *Seminars in Oncology Nursing* 1989 May; 5(2):109-13.

ABSTRACT A discussion of ethics issues for health care professionals, especially pediatric oncology nurses, who are caring for children and adolescents with cancer. Many different decisions must be made by patients and families. The health care professional must be aware of legal and ethical decisions relating to informed consent, treatment choices, therapeutic research, when and whether to use life sustaining treatment, and other essential issues for patients and families.

AUTHOR Holder AR.
TITLE **Childhood malignancies and decision making.**
SOURCE *Yale Journal of Biology and Medicine* 1992 Mar/Apr; 65(2):99-104.

ABSTRACT The author briefly explains some laws concerning the decision-making process to accept or refuse medical treatment for seriously ill minors. Parents cannot refuse "adequate" medical care for their child even if it violates religious beliefs. If parents continue to refuse, the child could be placed in a foster home for the duration of the treatment. Also, to allow adolescents more autonomy, "mature minors" may either consent to or refuse medical care without parental notification.

AUTHOR MacKenzie RG.
TITLE **Approach to the adolescent in the clinical setting.**
SOURCE *Medical Clinics of North America* 1990 Sep; 74(5):1085-95.

ABSTRACT The author addresses issues in adolescent development to enhance clinical care. The following issues are included: anatomy of pubertal change; anatomy of adolescent psychosocial change; social, legal, and political issues; and an approach to interviewing adolescents. Independence and dependence, peer group acceptance, sexuality and life goals, intimacy, and physical emancipation are considered to be primary psychological tasks of adolescence.

AUTHOR Neinstein LS.
TITLE ***Adolescent health care: A practical guide***. Second Edition.
SOURCE Williams & Wilkins: Baltimore, 1991:850.26

ABSTRACT This comprehensive textbook is written as a quick reference for all health-care professionals who care for teenagers in a clinical setting. An outline format is used with tables, checklists, charts, graphs, and sample questionnaires. Topics include accidents, eating disorders, contraception, sexually transmitted diseases, drug abuse, and psychosocial problems. Discussions cover normal growth and development, psychosocial development, interview techniques, health screening and evaluation, nutrition, and legal issues.

AUTHOR Owen MJ.
TITLE **What has the Social Security Administration done for you lately? Maybe more than you know.**
SOURCE *Exceptional Parent* 1991 Jun; 21(4):40-2.

ABSTRACT An overview of recent changes at the Social Security Administration (SSA) and how these changes will affect funding and services for children and youth with disabilities and their families. Public law 101-239 is discussed, as is a cooperative agreement between SSA and the National Parent Network on Disability.

AUTHOR Patterson D.
TITLE **Legal aspects of athletic injuries to the head and cervical spine.**
SOURCE *Clinics in Sports Medicine* 1987 Jan; 6(1):197-210.

ABSTRACT The author, a lawyer, reviews the history of sports injury litigation in athletics. Ironically, litigation in athletics in general, and football in particular, is inversely proportional to injury statistics. During the period when both neurologic and cervical injuries decreased, litigation increased. The author recommends various means to reduce risk, including the increased use of medical and paramedical personnel.

AUTHOR Perrin JM; Stein RE.
TITLE **Reinterpreting disability: Changes in supplemental security income for children.**
SOURCE *Pediatrics* 1991 Nov; 88(5):1047-51.

ABSTRACT An overview of the changes in the Social Security Administration's criteria for determining Supplemental Security Income (SSI) eligibility for children and youth with disabilities, following *Sullivan vs. Zebley*, the 1990 Supreme Court case. Implications for children and youth with disabilities and their families and opportunities for the pediatric community are discussed.

AUTHOR Rennert S; Parry J; Horowitz R.
BOOK ***AIDS and persons with developmental disabilities: The legal perspective.***
SOURCE American Bar Association: Washington, DC, 1989:109.

ABSTRACT This report discusses the ways current laws apply to persons with HIV infection and resulting developmental disabilities as well as persons with developmental disabilities who become infected with the virus. Topics covered include: antidiscrimination statutes; HIV testing, medical treatment, and informed consent; confidentiality and provider liability; isolation and involuntary civil commitment; and federal benefit and entitlement programs. Topics are discussed in relation to services and service delivery. Suggestions are made for further policy decisions. Available from the ABA, 1800 "M" Street, N.W., Washington, D.C. 20036. Cost: $18.

EDITOR Silber T.
BOOK ***Ethical issues in the treatment of children and adolescents.***
SOURCE Slack, Inc.: Thorofare, NJ, 1983:208.

ABSTRACT A collection of papers that addresses difficult questions arising in health care and research involving minors. The contributors balance opposing viewpoints and the concerns of all involved parties. Schowalter's classic paper on the adolescent patient's decision to die is reprinted. There are reviews of nondisclosure in cancer care, placebo therapy, development of ethics in school-age children, care of individuals with mental retardation, and consent to participation in research. Rotherberg's discourse on a possible national conspiracy against children, the ACCH policy guidelines for the administration of pediatric care facilities, and a summary of legal issues in pediatric practice complete this anthology.

AUTHOR Silber TJ.
TITLE **Ethical considerations in the care of the chronically ill adolescent.**
BOOK ***Chronic Illness and Disabilities in Childhood and Adolescence.***
EDITOR Blum RW.
SOURCE Grune & Stratton: Orlando, 1984:17-27.

ABSTRACT

This chapter focuses on ethical considerations regarding the physician-patient relationship. Ethical theory and adolescent moral development form the framework of the discussion. Specific areas addressed include physician obligations to patients and their parents, consent, noncompliance, euthanasia, confidentiality, truthful disclosure of information, treatment refusal, termination of care, and the use of minors as research subjects. Case reports are used to illustrate these points. (This book is out of print but is available in most medical libraries.)

AUTHOR Tremper CR; Kelly MP.
TITLE **The mental health rationale for policies fostering minors autonomy.**
SOURCE *International Journal of Law and Psychiatry* 1987; 10(2):111-27.

ABSTRACT

An excellent general article on the rationale for giving adolescents as much autonomy as possible for health care decisions. The authors argue that if the state wishes to foster adolescent mental health, especially nurturing their sense of self-worth while also rediucing self-destructive and anti-social behavior, government policies and institutions for minors should reflect a preference for autonomy.

AUTHOR Williams R; Singh TH; Naish J; et al.
TITLE **Medical confidentiality and multidisciplinary work: Child sexual abuse and mental handicap registers.**
SOURCE *British Medical Journal* 1987 Nov 21;295(6609):1315-9.

ABSTRACT

A group of doctors comment on the case of British mental handicap registers, i.e., the demand for patient's records by local social service agencies without consent. The general position is that because doctors are bound by confidentiality, the personal information should not be imparted unless it is non-controversial information already accessible through other means.

LEGAL ISSUES FOR THE FAMILIES AND ADVOCATES OF ADOLESCENTS WITH DISABILITIES

Guardianship, Estate Planning and Special Tax Considerations

AUTHOR Apolloni T.
TITLE **Guardianship: New options for parents**
SOURCE *Exceptional Parent* 1987 Nov; 17(8):24.

ABSTRACT This article reviews the concept of legal guardianship and discusses when guardianship is needed. Two approaches to guardianship, public and private corporations, are detailed along with a list of corporate guardianship programs.

AUTHOR Parry J.
TITLE **Life services planning for vulnerable persons.**
SOURCE *Mental and Physical Disability Law Reporter* 1986 Nov-Dec; 10(6):516-22.

ABSTRACT According to the author, life services planning is basically a comprehensive approach to traditional estate and financial planning that encompasses many of the additional concerns that adolescents with disabilities and their families, should have about the future. Those concerns include housing arrangements, social and health care needs, and conditions that can deprive individuals of their ability to make decisions for themselves. When utilized properly, life services planning can lessen or resolve anticipated, even unanticipated, problems having to do with personal autonomy, community support networks, unnecessary institutionalizations and inadequate financial resources.

AUTHOR Russell LM.
BOOK ***Alternatives. A family guide to legal and financial planning for the disabled.***
SOURCE First Publications: Evanston, IL, 1983:194.

ABSTRACT This handbook was prepared by an attorney who has a sibling with mental disablities to assist parents in planning for future care of their children with disabilities. The author reviews all aspects of wills, guardianship, trusts, government benefits, tax deductions, insurance, and investments. He lists national organizations with information related to many specific disabilities and adds a glossary of legal and financial terms.

AUTHOR: Russell LM; Joseph S; Grant A; et al.
TITLE: **Planning for the future.**
SOURCE: American Publishing Company: 814 S. Boulevard, Evanston, IL 60202, 1993:300.

ABSTRACT: A complete and authoritative source of information on life and estate planning for a family member who has a disability.
For information, call 800-247-6553.

AUTHOR: Sigman G.
TITLE: **Advance directives.**
SOURCE: *Connections* (Newletter of the National Center for Youth with Disabilities) 1992 Winter; 2(3):5.

ABSTRACT: Advance directives (living wills and durable power of attorney being the two most common forms) were conceived for and most often developed for the elderly. Adolescents and young adults with severe chronic illness, however, face the same end-of-life issues. Patients age 18 and older are required by law (the Patient Self-Determination Act of 1990) to be given information about advance directives, although the author argues that age 18 is highly arbitrary. This commentary suggests that perhaps the greatest utility advance directives provide to adolescents with significant chronic conditions may well be to facilitate the process of comunication with the patient's family and health-care professional.

AUTHOR: Wood L.
TITLE: **Estate planning for parents of children with disabilities.**
SOURCE: *Exceptional Parent* 1992 Nov/Dec; 22(8):18-20.

ABSTRACT: This article addresses estate planning for parents of children with disabilities, especially alternatives to conventional estate planning techniques. This article also contains a list of questions for parents to ask their estate planning attorney.

Life Ending Issues: Legal and Ethical Decision Making

AUTHOR: Freyer DR.
TITLE: **Children with cancer: Special considerations in the discontinuation of life-sustaining treatment.**
SOURCE: *Medical and Pediatric Oncology* 1992; 20(2):136-42.

ABSTRACT: With the intent to relieve some of the "undue burden" upon the patient as well as the family, the author raises special considerations in the termination of life-sustaining treatment for children with cancer. Included in the decision to discontinue treatment are the issues of the patient's well-being and autonomy, especially as the minor becomes a mature adolescent.

AUTHOR Goldman GM; Stratton KM; Brown MD.
TITLE **What actually happened: An informed review of the Linares incident.**
SOURCE *Law, Medicine, and Healthcare* 1989 Winter; 17(4):298-307.

ABSTRACT The report provides facts and legal opinions regarding Rudy Linares' decision to disconnect his son's ventilator, thus allowing the child to die. The review defines some medical terminology, clarifies legal issues and provides a comprehensive legal framework in which to view this case.

AUTHOR Hoberman HM.
TITLE **The impact of sanctioned assisted suicide on adolescents.**
SOURCE *Law and Medicine* 1988 Fall; 4(2):191-205.

ABSTRACT An examination of the issues surrounding a potential right to self-termination among persons with terminal illnesses or chronic disabilities and whether that right should be extended to adolescents. Adolescent development and empirical findings regarding suicide among both adults and adolescents serve as the foundation for analysis. Attention is given to differentiating myths or popular perceptions from empirical findings.

AUTHOR Lantos JD; Miles SH.
TITLE **Autonomy in adolescent medicine. A framework for decisions about life-sustaining treatment.**
SOURCE *Journal of Adolescent Health Care* 1989 Nov; 10(6):460-6.

ABSTRACT Physicians face legal, ethical and medical decisions when deciding whether to withhold life-sustaining treatment from adolescents. The article presents a model that can be used to determine the decision-making capacity (DMC) of adolescent patients. Once there has been accurate determination of the medical indications for treatment, including prognosis with and without treatment, and when there has been sufficient communication between physician and patient, the model can assist the physician and patient in determining the adolescent's ability to give informed consent for treatment.

AUTHOR Leikin SL.
TITLE **An ethical issue in pediatric cancer care: Nondisclosure of a fatal prognosis.**
SOURCE *Pediatric Annals* 1981 Oct; 10(10):37-45.

ABSTRACT Discussion of patient and parent rights based on a 13-year-old patient, with developmental implications.

AUTHOR Maynard FM; Muth AS.
TITLE **The choice to end life as a ventilator-dependent quadriplegic.**
SOURCE *Archives of Physical Medicine and Rehabilitation* 1987 Dec; 68(12):862-4.

ABSTRACT Case study of a 19-year-old male who chose to be disconnected from his ventilator 25 months after the diving accident which caused his total motor and sensory quadriplegia. Physical, medical, psychosocial, and legal circumstances are detailed. Rehabilitation staff were said to be particularly disturbed by the patient's decision due to his wealth of resources not often available to individuals who have quadriplegia and are ventilator-dependent (eg., social support, assistive equipment, accessible home services, personal assets). The authors suggest that working toward a legal end to his life, one that would not cause his family undue hardship, may have given meaning to this patient's post-injury experience.

THE CRIMINAL JUSTICE SYSTEM AND THE ADOLESCENT/ YOUNG ADULT WITH DISABILITIES

AUTHOR Benedek E.
TITLE **Psychiatry and juvenile law.**
SOURCE *Psychiatric Clinics of North America* 1983 Dec; 6(4):695-706.

ABSTRACT Review of issues involved in civil commitment, child custody and divorce, juvenile delinquency, competency of minors, malpractice in child psychology.

AUTHOR Conley RW; Luckasson R; Bouthilet GN.
TITLE **The criminal justice system and mental retardation. Defendants and victims.**
SOURCE Paul H. Brooks: Baltimore, 1991:336.

ABSTRACT This book is a comprehensive guide for those working with individuals who have mental retardation and are involved in the criminal justice system. The procedures for individuals with mental retardation who are either perpetrators or victims of crime are discussed. Rehabilitation options are debated, and several model programs for prisoners are described. Included are epidemiological studies which show factors that contribute to criminal involvement.

AUTHOR Gilby R; Wolf L; Goldberg B.

TITLE **Mentally retarded adolescent sex offenders. A survey and pilot study.**

SOURCE *Canadian Journal of Psychiatry* 1989 Aug; 34(6):542-8.

ABSTRACT

A survey of sexual problems evidenced by adolescent patients at a psychiatric facility indicated that these adolescents had experienced many such problems regardless of intellectual capacity. Adolescents with mental retardation were found to be more likely to engage in inappropriate non-assaultive sexual behavior such as public masturbation. When adolescent sex offenders with mental retardation were studied, they differed from those without mental retardation in the following ways: they offended equally against males and females (rather than predominantly against females); they were more likely to offend against same-age or older victims; they were less likely to show a history of family dysfunction or delinquency; and they were more likely to display EEG abnormalities. Treatment considerations are suggested, and data are compared with previous research findings.

AUTHOR Grande CG.

TITLE **Educational therapy for the failing and frustrated student offender.**

SOURCE *Adolescence* 1988 Winter; 23(92):889-97.

ABSTRACT

Different modifications and approaches are suggested in this article to treat the "failing and frustrated" youth offender, including those with disabilities. The author points out that students with disabilities are not excluded from the juvenile and criminal justice settings. One national survey indicated that 42% of the population of juvenile correctional institutions are comprised of adolescents with disabilities. Although many types of disabling conditions were represented among the incarcerated, the three highest incidence rates were among the emotionally disturbed (16.23%), the learning disabled (10.59%) and the educable mentally retarded (7.69%). Educational therapy methods noted include classroom management systems, curriculum and instructional adjustment counseling and support services as well as alternative educational programming.

AUTHOR Lewis KA; Schwartz GM; Lanocone RN.

TITLE **Service coordination between correctional and public school systems for handicapped juvenile offenders.**

SOURCE *Exceptional Children* 1988 Sep; 55(1):66-70.

ABSTRACT

Research was conducted to examine the transition of juvenile offenders with disabilities as they move through juvenile correctional facilities and return to public schools. Findings showed a lack of continuity in the transition between the correctional facility public schools. The authors emphasize the importance of coordinating transition for youth offenders with disabilities.

AUTHOR Lundervold DA;Young LG.

TITLE **Treatment acceptability ratings for sexual offenders: Effect of diagnosis and offense.**

SOURCE *Research in Developmental Disabilities* 1992; 13(3):229-37.

ABSTRACT Findings indicate that regardless of whether sexual offenders have mental retardation or not, both should receive similar punishment. Incarceration was chosen as the best "treatment." The author believes laws should be clarified as to such issues but also is concerned that sexual offenders with mental retardation might not benefit as much from incarceration as they would from behavior analysis treatment.

AUTHOR Myers BA.

TITLE **Treatment of sexual offenses by persons with developmental disabilities.**

SOURCE *American Journal of Mental Retardation* 1991 Mar; 95(5):563-9.

ABSTRACT The author discusses the clinical and ethical dilemmas involved in the management of sexual offenses committed by individuals with mental retardation. Medication is suggested to provide the most successful treatment for individuals with paraphilias (certain types of sexual offenses). A case report is presented of a young man with mild mental retardation who engaged in pedophile and was successfully treated with medroxyprogesterone acetate (MPA). The author emphasizes individual rights and states that anti-androgenic agents such as MPA should not be used indiscriminately.

AUTHOR Perske R.

TITLE ***Unequal justice? What can happen when persons with retardation or other developmental disabilities encounter the criminal justice system.***

SOURCE Abingdon Press: Nashville TN, 1991:122.

ABSTRACT Perske raises questions about the treatment of persons with disabilities in the criminal justice system. Using observation and case studies, he describes numerous encounters of those caught in "the system." The individuals are presented as vulnerable, defenseless and misunderstood victims who often seem to be treated unequally when charged with a crime.

AUTHOR Praiss DM.

TITLE **Constitutional protection of confessions made by mentally retarded defendants.**

SOURCE *American Journal of Law and Medicine* 1989; 14(4):431-65.

ABSTRACT This article addresses the special needs of persons with mental retardation in the criminal justice system. The author argues that suspects with mental retardation require careful explanation of *Miranda* rights in order to truly understand them. The intellectual and adaptive deficiencies that characterize mental retardation also necessitate an inquiry into a valid waiver that accounts for these disabilities. Especially important for suspects with mental retardation is that the right to counsel attach as early as possible, indeed perhaps as early as the precustodial stage of an investigation. The author submits that early access to counsel is probably the best assurance that a waiver of constitutional rights by a person with mental retgardation is, in fact, voluntary, knowing and intelligently given.

AUTHOR Russell T; Boswell CF.

TITLE **A comparison of selected demographic, educational, and behavioral factors among adolescent mentally retarded offenders and adolescent mentally retarded nonoffenders.**

SOURCE *Journal of Offender Counseling, Services and Rehabilitation* 1986 Spring; 10(3):5-24.

ABSTRACT A comparison study of 21 demographic, educational and behavioral variables between 40 adolescents with mental retardation (MR) identified as offenders and 40 adolescents with MR identified as nonoffenders. Results indicated that the variables, when combined, showed significant differences between groups. Significance decreased when the variables were viewed in isolation. Researchers recommend further studies to help identify risk factors for adolescents with MR that increase their potential for juvenile delinquency.

EDITOR Schetky DH; Benedek EP.

BOOK ***Emerging issues in child psychiatry and the law.***

SOURCE Brunner/Mazel: New York, 1985:357.

ABSTRACT In this sequel to a previous text, the authors have collected papers discussing new developments affecting the interface between law and child health care, especially mental health care. Topics include children's consent/refusal in psychiatric treatment, cancer therapy, and organ transplantation, child-custody disputes and mediation, gay parents, the juvenile offender, legal issues and schools, legal and therapeutic parameters in working with cult members, and approaches to children traumatized by violence.

AUTHOR Shepherd, Jr. RF.
TITLE **Juvenile justice.**
SOURCE *Criminal Justice* 1991 Spring; 48-49.

ABSTRACT

Few cases have addressed the question of capacity in juvenile court, and the author suggests that issue should be raised more often. A psychiatric or psychological examination should be sought in every juvenile court case where there are some questions about the adolescent's mental capacity or mental responsibility. While the court may not recognize a plea of insanity per se, a judge may be willing to handle the disposition (or sentencing) phase of a case involving mental illness in a fashion that focuses more on the mental health needs of the adolescent than in a typical juvenile disposition.

AUTHOR Traynelis-Yurek E; Giacobbe GA.
TITLE **Unremediated learning disabilities and reincarceration.**
SOURCE *Journal of Offender Counseling, Services and Rehabilitation* 1988; 13(1): 163-74.

ABSTRACT

A study investigating the reincarceration rate of a group of 56 adolescents with learning disabilities (LD) at the Elk Hill Farm, a residential facility for young men with emotional, educational, and legal problems. Results indicate that students receiving educational remediation and social skills training had significantly lower recidivism rates. Academic remediation appeared to have a greater impact on later incarceration than the length of time that the adolescent with LD had been involved with the law.

RESOURCE MATERIALS

TITLE **ABA juvenile and child welfare law reporter.**
CONTACT American Bar Association, Center on Children and the Law
ADDRESS 1800 M Street NW; Washington, DC 20036
PHONE 202-331-2256

ABSTRACT

A monthly summary of major court cases, legislative updates, reports and articles on major legal issues facing adolescents, their parents and professionals working with them. For subscription information and information about other publications of the center, call 202-331-2256.

AUTHOR | Brakel SJ; Parry J; Weiner BA.
BOOK | ***The Mentally Disabled and the Law*** (3rd edition).
SOURCE | American Bar Foundation: Chicago, 1985:845.

ABSTRACT | A comprehensive text on mental disability law that includes juveniles with mental illness as an integrated component. This book contains the following chapters: Historical Trends; Involuntary Institutionalization; Voluntary Admission; Discharge and Transfer; Rights of Institutionalized Persons; Treatment Rights; Incompetency, Guardianship, and Restoration; Decision-Making Rights over Persons and Property; Family Laws; Provider-Patient Relations: Confidentiality and Liability; Rights and Entitlements in the Community; and Mental Disability and Criminal Law.

AUTHOR | Clark, J; Manes J.
TITLE | **The Advocate's Guide to SSI for Children**
SUPPLIER | Mental Health Law Project
ADDRESS | 1101 - 15th Street NW, Suite 1212; Washington, DC 20005
PHONE | 202-467-5730

ABSTRACT | A comprehensive manual designd to enable advocates, health care and social service providers to work with the laws, regulations, policies, and procedures that govern the eligibility of children and youth with disabilities for Supplemental Security Income (SSI). It includes application and appeal procedures, processes for establishing financial and disability-based eligibility, post-eligibility issues, *Zebley* Benefits, and SSI's relationship to other federal programs for children. Purchase: $75.00.

TITLE | ***Disability benefits in brief.***
CONTACT | Disability Benefits Association
ADDRESS | 495 East Ellefson Street; Iola, WI 54945
PHONE | 715-445-4755

ABSTRACT | *Disability Benefits in Brief* is a bi-monthly newsletter that explains Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), programs of the Social Security Administration. It is published six times per year by the Disability Benefits Association. The newsletter is devoted to the practical understanding of the Social Security system, especially as it relates to benefits levels and is perhaps the only comprehensive publication devoted to tracking the many policies of SSA. Alternative formats are available. Cost of a one-year subscription is $35.

AUTHOR Herr SS; Levy JM.
BOOK ***Issues in human rights. A guide for parents, professionals, policymakers and all those who are concerned about the legal and civil rights of mentally retarded and developmentally disabled people.***
SOURCE YAI Press: Young Adult Institute, Publications Department
460 West 34th Street; New York, NY 10001-2382, 1989.

ABSTRACT A comprehensive monograph focusing on the human and civil rights of people with disabilities. Topics include: protecting human and legal rights; searching for enforcement strategies; implications of recent Supreme Court decisions; Rogers vs. Mills and the right to refuse treatment; Romeo vs. Youngberg and the right to minimal training.

TITLE **Legal rights: The guide for deaf and hard of hearing people.**
SUPPLIER The National Center for Law and Deafness
400 Florida Avenue NE; Washington, DC, 1992:297.
PHONE 202-651-5373

ABSTRACT This resource addresses the most common legal problems that arise between persons with deafness and the primary institutions of society, including access to education, employment, medical care and social services. This edition has been updated and includes a chapter devoted to the Americans with Disabilities Act (ADA). Purchase: $19.95 (Stock #2837).

AUTHOR Romano JL.
TITLE ***Legal rights of the catastrophically ill and injured: Planning for the future.*** **4th edition.**
CONTACT Sandra Pinyard
ADDRESS 200 Four Falls Corporate Center, Suite 310; West Conshohocken, PA 19428.
PHONE 215-834-8500

ABSTRACT This reference work provides a wealth of information and numerous resources for those advocating for people with disabilities and the protection of their legal rights, especially their rights to medical benefits. The book provides an overview of many legal, medical and insurance issues affecting people with catastrophic illnesses and injuries and their families. Thirty-nine specific topics are covered, from when to consult an attorney, guardianship, insurance benefits, specific severe disabling injuries and chronic illness to taxes and estate planning. Copies of this book are free.

AUTHOR	Rosenfeld L; Worley G; Lipscomb J.
BOOK	***Saving money and getting help: Advice for families of children with spina bifida and other health problems.***
SOURCE	Spina Bifida Association of North Carolina and Duke University: Durham NC, 1987:25.
ADDRESS	Spina Bifida Association of North Carolina 207 West Main Street; Mayodan, NC 27027
PHONE	800-847-2262 or 919-548-4888
ABSTRACT	This manual was designed as a tool for parents seeking care and assistance for their children. It includes information on the following: expected costs of raising a child with spina bifida; tips for reducing expenses; ways to increase private insurance coverage; government programs that can address medical costs; programs that provide services to children with disabilities and their families; income tax reductions available; advocacy, legal aid, and parent support programs; suggestions for improving financial management; and long-term planning for financial security. The example of spina bifida is generalizable to other chronic illnesses. A companion manual for social workers and other helping professionals is also available.

AUTHOR	Sauer AJ.
TITLE	**Tax considerations for parents of disabled children.**
SOURCE	*Meeting Ground* 1992-93 Winter; 5-6 (Quarterly Newsletter of Courage Center)
CONTACT	Annette Pentel
ADDRESS	Courage Center; 3915 Golden Valley Road; Golden Valley, MN.
PHONE	612-520-0438
ABSTRACT	The author, a CPA, discusses the potential tax savings for parents of youth with chronic conditions that can be realized from certain tax credits or by deducting medical expenses. Most parents take the usual deductions; those frequently missed include expenses required for the care and treatment of a disabled child. Included in these additional, often overlooked, costs are: 1) capital expenditures to modify or adjust a home or items of personal property; 2) the costs of special education and training; and 3) other expenses including certain transportation costs for providing medical care. Also included is a list of IRS publications available for further information. This article is rewritten and updated annually; the article for the 1993 tax filing season will appear in the 1993-94 Winter issue of *Meeting Ground.*

TITLE	**Social Security and Supplemental Security Income Benefits for Children with Disabilities.**
SUPPLIER	The Arc; National Headquarters
ADDRESS	500 East Border Street, Suite 300; Arlington, TX 76010
PHONE	817-261-6003
ABSTRACT	A Q&A pamphlet on the topic of Social Security and Supplemental Security Income (SSI) for children and adolescents with disabilities. Questions and answers address the following: benefits, eligibility, the definition of "disabled," severe disabilities, HIV infection, application procedures, and alternatives.

TITLE	**Symposium on developmental disabilities law.**
SOURCE	*Kansas Law Review* 1991 Spring; 39(3).
ADDRESS	Beach Center on Families and Disability; Institute for Lifespan Studies 3111 Haworth Hall; Lawrence, KS 66045
PHONE	913-864-7600
ABSTRACT	A special symposium issue on developmental disabilities law. Topics include: the rights of individuals with disabilities and their families, including discussion of the "Nancy Cruzan" case; ways families can negotiate the social security eligibility maze; and AIDS and its implications for people with developmental disabilities. The symposium also addresses the new Kansas state policy of "family support." Purchase: $8.00.

AUTHOR	Tucker BP; Goldstein BA.
TITLE	***Legal rights of persons with disabilities. An analysis of federal law.***
SOURCE	LRP Publications: 747 Dresher Road, Suite 500; PO Box 980 Horsham, PA 19044-0980, 1991:746.
ABSTRACT	This book is a comprehensive examination of current federal laws pertaining to rights of persons with disabilities. The treatise covers the Americans with Disabilities Act; the U.S. Constitution; Sections 504, 503, and 501 of the Rehabilitation Act; Fair Housing Act; Architectural Barriers Act; Education for all Handicapped Children Act; Urban Mass Transportation Act; Federal Aid Highway Act; and laws affecting newborns who are disabled. A valuable resource for employers, educators, advocates, attorneys, and others who are interested in the rights of those with disabilities. For more inormation, call 800-341-7874.

AUTHOR	Turnbull HR; Turnbull AP; Bronicki GJ; et al.
BOOK SOURCE	***Disability and the Family: A Guide to Decisions for Adulthood.*** Paul H. Brookes: Baltimore, 1989:432.
ABSTRACT	This book gives practical information and steps for planning for the future of adolescents with disabilities. It includes legal, social-interpersonal, vocational and residential options. Methods for self-assessment, self-advocacy, and lists of resources to assist in planning are included.

AUTHOR U.S. Department of Education.
BOOK ***Summary of existing legislation affecting persons with disabilities.***
SOURCE Office of Special Education and Rehabilitative Services, Clearinghouse on the Handicapped, 1992:235.
ADDRESS 330 C Street SW; Washington, DC 20202-2524
PHONE 202-205-8241

ABSTRACT This publication provides a comprehensive summary of federal legislation enacted as of 1991 that affects persons with disabilities. Included is legislation related to education, employment, health, housing, income, nutrition, social services, transportation, and vocational rehabilitation. Also included is a basic overview of each law's purpose and structure, the major programs authorized under each statute, and a history of each law that affects persons with disabilities. There is no charge for this publication.

AUTHOR Zavos M.
BOOK ***Directory of legal resources for people with AIDS and HIV.***
SOURCE American Bar Association, AIDS Coordination Project
1800 M Street NW, Washington, DC 20036
PHONE 202-331-2243.

ABSTRACT A comprehensive listing of programs and organizations that provide free legal services to people with AIDS or HIV. The directory is organized by state and describes projects. Users can obtain a wide range of legal services from projects that are listed. Purchase: $18 plus $3.95 shipping and handling.

RESOURCES-PROGRAMS

NAME **Bazelon Center for Mental Health Law**
CONTACT Lee A. Carty
ADDRESS 1101 Fifteenth Street NW, Suite 1212; Washington, DC 20005-5002
PHONE 202-467-5730

ABSTRACT Formerly known as the Mental Health Law Project, this 20-year-old national advocacy organization has been the leading legal advocate for people with mental disabilities. It has been involved in establishing civil and constitutional rights of people with mental disabilities ranging from the rights to due process, to protection from harm and to appropriate treatment and education. Recently, the center has been heavily involved in implementing the outreach provisions of the *Zebley* decision, the case that changed the definition of SSI eligibility for children and adolescents. The center publishes various materials deaing with the legal rights of adolescents and young adults with mental disabilities. For further information, contact Lee Carty at the number above.

NAME **Center for Public Representation**
ADDRESS 121 South Pickney Street; Madison, WI 53703.
PHONE 608-251-4008

ABSTRACT

The Center for Public Representation is Wisconsin's oldest non-profit public interest law firm. Through its publishing house arm, CPR Press, it carries out its mission of empowering citizens by educating them through the publication of books, guides and pamphlets that lay people can readily understand. The center enables individuals, families and advocates to learn about, understand and interpret laws and regulations that affect them. Several of the center's publications deal with the concerns and issues of adolescents with chronic conditions. Call the Center to request a catalog of legal manuals and consumer publications.

NAME **Commission on Mental and Physical Disability**
AFFILIATION American Bar Association
ADDRESS 1800 M Street NW, Suite 200; Washington, DC 20036
PHONE 202-331-3884

ABSTRACT

The Commission's mission is "to fulfill the ABA's Commitment to justice and the rule of law for persons with mental and physical disabilities. Its most prestigious project is publication of the *Mental and Physical Disabilities Law Reporter*, a leading law journal. Other activities include training, technical assistance, publications, and operation of its Disability Law Network, a disability law database containing its extensive collection of case materials.

NAME **National Center for Youth Law**
ADDRESS 114 Sanome Street, Suite 900; San Francisco, CA 94104-3820
PHONE 415-543-3307

ABSTRACT

This non-profit organization provides specialized assistance to attorneys and advcates who work on behalf of poor children and adolescents, including those with chronic illness or disability. The National Center for Youth Law (NCYL) works to protect the rights of children and adolescents trough litigation, consultation, publications, training programs, and various support services. *Youth Law News*, NCYL's newsletter, is published six times per year.

National Center for Youth with Disabilities/ Society for Adolescent Medicine

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